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A lump in throat: Qualitative study on hospitalization-related experiences among the parents of children with cancer

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Original Article

Abstract

BACKGROUND: As the second leading cause of death, cancer is among the most stressful life events. It affects not only the afflicted patients, but also their families. Hospitalization of children with cancer faces their parents with many challenges and problems. This study was made to explore the hospitalization-related experiences among the parents of children with cancer.

METHODS: This qualitative phenomenological study was made in 2015–2016 in the hematology and oncology care unit of a teaching hospital located in Qazvin, Iran. Sampling was done purposefully and was ended once data saturation was achieved. Consequently, fifteen parents of children with cancer were recruited. Semi-structured interviews were held for data collection. The data were analyzed through the seven-step hermeneutic data analysis process proposed by Diekelmann and Ironside (1998).

RESULTS: Two main categories were extracted from the data which included "the shadow of government administration" and "the role of support systems". The former refers mainly to accommodations in hospital settings and the process of clinical care delivery, while the latter points to the parents' psychological experiences of presence in hospital settings. These themes came under the overarching main theme of "lump in throat: the suffering of the parents of children with cancer".

CONCLUSION: Study findings reveal that parents' experiences of hospitalization greatly depend on their perceptions of the environmental conditions of hospital settings. Moreover, the findings showed that negative hospitalization-related experiences could lead to many adverse consequences for patients, families, and healthcare providers.

KEYWORDS: Cancer, Children, Parents

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Introduction

Cancer is among the leading causes of death in the world so that after cardiovascular disease (CVD), it is called as the major epidemic of the present era.[1] Cancer is the third cause of death in our country, Iran, the second cause of childhood mortality in the Third World countries,[2,3] and among the most stressful life events.

Cancer-induced changes can affect not only the afflicted patients, but also their siblings, parents, and families.[4] Seriously-ill children who suffer from cancer need prolong hospitalizations and hence, they are frequently separated from their natural environment and are transferred to an unfamiliar environment.[5] Besides, different and complex treatment

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procedures exhaust children,[6] cause them great stress, and reduce the life quality of their parents who are usually their chief caregivers.[7]

Abundant evidence exists for the pivotal role of patients' significant others in the processes of treatments, illnesses, and patients' death. Nonetheless, healthcare providers solely focus on patients' needs.[8] Families of children who suffer from specific diseases such as cancer usually face problems such as restlessness, social isolation, frequent hospitalizations, and feelings of guilt, anger, and depression.[9] Litzelman et al. reported parental stress caused by their children's illnesses as a significant factor behind the reduction of the quality of life among the parents of children with cancer.[10]

Although children's hospitalization-related needs are important, fulfilling their parents' needs is also of great importance. Parents whose needs are effectively and adequately fulfilled are more capable of coping with their children's illnesses.[11,12] In order to provide quality care to their sick children, parents need to be supported actively, their concerns should be understood and alleviated, and they have to be involved in the process of care giving to their children.[12] The most basic needs of these parents are information, support, and hope.[13] According to Sayin and Aksoy, family members are usually worried about care delivery to their patients and thus, they need care-related information before making any attempt to fulfill their own other needs.[14] Fry and Warren[15] and Wong et al.[16] also noted that the most important need of critical care family members was the need for information about the course and prognosis of their patients' illnesses. The delivery of such information is among the responsibilities of healthcare providers and authorities.[17]

Many studies have been made so far into the parents' experiences of their children's illnesses. For instance, Majdalani et al. explored parents' experiences of their children's hospitalization in pediatric intensive care units (PICUs).[18] Plakas et al. also focused on the experiences of the parents of critically-ill patients in Greece.[19] Besides, Jadidi et al. did a study to explore the experiences of the parents of children with leukemia and reported that those exploring parents' experiences helped raise their hope and improve the effectiveness of care services.[20] In addition, information about the experiences and the satisfaction of patients can play a critical role in enhancing the quality of care and improving patients' health and recovery.[21] This study was made to explore hospitalization-related experiences among the parents of children with cancer.

Materials and Methods

This qualitative phenomenological study was made in 2015–2016 in the hematology and oncology care unit of Qods Teaching Hospital, Qazvin, Iran. Sampling was done purposefully through which, fifteen parents of children with cancer were recruited.

Semi-structured face-to-face personal interviews were held in order to collect study data. An interview guide was used to manage the flow of the interviews. Interview guide included the experience of the first presence in the hospital, the behavior of medical and non-medical staff, parental involvement in the process of treatment and clinical education, mental relaxation in the hospital, criticism of the personnel, and etc. The inclusion criteria for participants were at least two cycles of treatment in the hospital for the care of the sick children and the interest in participating in the study. Interviews were held by the first author and were continued until data saturation was achieved. The length of the interviews was 35 minutes, on average. All interviews were conducted in a room in the hospital and were recorded using a digital recorder.

The data were analyzed through undergoing the seven-step hermeneutic data analysis

process proposed by Fitzpatrick and Kazer.[22] Initially, the contents of all recorded interviews were transcribed. In the second step, the interview transcripts were perused to obtain an understanding about them. Thereafter, the main ideas of each interview transcript were identified and coded. The extracted codes which were similar and pertained to same concepts were sorted into categories. The categories were in turn grouped into themes based on the similarities and the differences among them. In the fifth step, we attempted to validate the findings through referring to the main data. After that, the main themes were described and finally, the findings were provided to the participants and they were asked to approve the congruence between the data and their own experiences.

The participants were provided with information about the aims and the methods of the study and they were ensured about the confidentiality and the anonymity of their data. They read and signed the consent form of the study. At the beginning of each interview, the intended interviewee was informed that participation in and withdrawal from the study were voluntary. Besides, the interviews were anonymized and coded with numerical codes. We also ensured the participants that their information would be used solely by the researchers and for research purposes.

Results

Most of the participants were mothers whose age ranged from 21 to 49 years and held primary to master's degrees. They referred to the study setting from different cities located in Qazvin Province. Most of them were housewives and only one of them was a white-collar worker. Their experiences of attending hospital settings fell into two main categories of "the shadow of government administration" and "the role of support systems", each of which had four subthemes (Table 1). All of these themes and subthemes came under the overarching main theme of "lump in throat: the suffering of the parents of children with cancer".

1. The shadow of government administration

Because of the gap between the public and the private healthcare delivery systems in Iran, clients have a negative attitude towards public hospitals (such as the study setting) and evaluate care services provided by such centers to be of lower quality compared with private health centers. In other words, clients consider private and public healthcare delivery centers in Iran to be patient-centered and physician-centered, respectively. Such an attitude makes clients to prefer private centers over public ones.

1.1. Negative attitude towards public hospitals: The participants noted that in public hospitals, staffs were less committed to quality care delivery. Nonetheless, they were compelled to refer to public hospitals due to financial burdens associated with their children's illnesses and inadequate private chemotherapy and cancer care services. In other words, they had no more option but to refer to public hospitals in order to receive cancer care services.

"This is a public hospital and thus, we shouldn't have great expectations" (P. 14).

Table 1. The main themes and subthemes of the study

Subthemes	Main themes	Overarching theme
1. Negative attitude towards public hospitals	The shadow of government administration	Lump in throat: the suffering of the parents of children with cancer
2. Parents' non-involvement in the process of treatment		
3. The role of accommodations in alleviating sufferings		
4. Poor patient education		
1. The suffering caused by indetermination	The role of support systems	
2. Seeking for peace and serenity		
3. Lump in throat		
4. The effects of other parents' presence		

1.2. Parents' non-involvement in the process of treatment: According to the participants, there is no effective plan for involving parents in the process of treatment and care delivery. Most of the participants were unfamiliar with the concept of participatory care and considered participation as the execution of physicians' orders and looking after their children. Consequently, they preferred physician-centered approach to treatment and allowed physicians to make all treatment-related decisions.

"We don't have as much information as our doctors and hence, we ask them to make decisions. Consequently, they make treatment-related decisions based on their own preferences" (P. 3).

1.3. The role of accommodations in alleviating sufferings: Hospitals have to include accommodations and facilities in order to fulfill family members' needs and prevent them from experiencing added suffering and burdens. Nonetheless, most participants complained of the lack of accommodations in hospitals. They noted that not only hospitals provided inadequate accommodations to family members, but also there were limited accommodations and facilities for hospitalized children. They highlighted the significant roles of play and entertainment in boosting sick children's morale, distracting them from their pain and agonies, and enhancing their endurance. Nonetheless, they believed that there were limited recreational and play facilities in hospitals for children.

"There are no facilities here for family members to take a rest or sleep. We expect hospitals to provide family members at least with a sofa in patients' rooms (P. 11). When my child and I stay here for one week, my child cries a lot for going back home and playing. A play room here can entertain him, provide him with the opportunity to play with other children, and distract his attention from home" (P. 13).

1.4. Poor patient education: According to the participants, hospitals provide no well-organized educations to family members about looking after children with cancer. They noted that they had only received superficial and ordinary educations. Parents who had asked for detailed information had been simply referred to other parents or the internet. Mismatch among information acquired from different sources had also caused some problems for the participating parents. For instance, there was a possibility of disease aggravation due to mismatch between educations provided by a nurse and a resident.

"They provided us with no education even about how to give a sponge bath to our children. I gradually and personally collected information and understood how to give the bath effectively in order to reduce my child' fever" (P. 11).

2. The role of support systems

The second main theme of the study was related to the role of support systems. The subthemes of this main theme are explained in what follows.

2.1. The suffering caused by indetermination: The major reason behind the participants' fears and concerns was the misconception that '*Cancer is always fatal*'. Parents whose children had only recently developed cancer tended to acquire more detailed information about the disease, its prognosis, and the course of its treatment in order to alleviate their own psychological wounds. However, healthcare providers avoided providing them with the necessary information. Most of the participants complained about the unresponsiveness of healthcare providers, particularly their physicians. Meanwhile, some of the participants believed that healthcare providers' unresponsiveness was advantageous to family members. Participant 14 whose child had been recently hospitalized in the study setting commented:

"Whenever I ask them about the results of laboratory tests, they answer: 'It is good'. Therefore, I feel compelled to check the results in my child's medical records. They also disagree with and disapprove of me when I check my child's medical records" (P. 14).

2.2. Seeking for peace and serenity: The participants highlighted the importance of having psychological security in hospital settings and noted that hospitals needed to adopt strategies to provide hospitalized children and their family members with such security.

Nonetheless, they were dissatisfied with their psychological security, peace, and serenity in hospitals. Some of them even bitterly complained about lack of silence in hospital wards. In order to alleviate such problems, the participants tended to strengthen their relationships with God rather than seeking help from healthcare providers or other sources of support. Consequently, they noted that in hospital settings, patients and family members needed to have easy access to facilities for doing religious rituals in order to have psychological security. However, they had limited, if any, access to such facilities. Participant 10 referred to the crowdedness and noisiness of hospital settings by saying:

"We need to feel serene in our patients' rooms. However, the door is always open and many people come and go. Nonetheless, nobody has the permission to close the door because they (hospital staffs) disagree with that" (P. 10).

Participant 13 also highlighted the need for religious facilities and said:

"There should be a prayer room here. We need somewhere to worship God, relate with Him, and confabulate to Him. However, there isn't even a prayer book here" (P. 13).

2.3. Lump in throat: The participants' experiences showed that almost in most cases, there had been no strong relationship between them and their healthcare providers, particularly physicians. According to them, the main reason behind such a poor relationship was their inability to establish strong relationship due to lack of information. Some of them also referred to healthcare providers' improper conduct as the reason and noted that the atmosphere of such relationships was tense and full of fear. They avoided criticizing healthcare providers or making complaints because it might result in the discontinuation of the treatments for their children. Therefore, they experienced an added stress due to their inability to communicate with healthcare providers.

"We ask them but they don't mind. We fear that our insistence results in their obstinacy and ruins our relationships with them. You know, we need to refer to hospital frequently and for a long time and hence, they may avoid providing quality care to our children and fulfilling their needs if we insist on our requests" (P. 10).

2.4. The effects of other parents' presence: Lengthy hospitalization of children with cancer and the need for their parents' constant companionship with them create a need for a source of psychological support. Healthcare providers' heavy workload and their poor relationships with patients and family members made our participants avoid referring to and expecting sympathy from them. Alternatively, they established relationships with each other in order to share their feelings. Most of them noted that the presence of other people with the same problems as their own had positive effects on their morale.

"Here, I see that other hospitalized children have the same problems as my own child. Besides, some mothers share their information about remedies for children's problems. Such factors boost my morale and make me happy" (P. 5).

Discussion

This study was made to explore hospitalization-related experiences among the parents of children with cancer. One of the study findings was parents' negative attitude towards public hospitals and negative experiences of attending such hospitals so that some of them referred to their poor access to private hospitals as the main reason behind choosing public ones. Poor environmental conditions, healthcare professionals' lack of professional experience, and shortages of equipment and facilities were among the factors behind the participants' negative attitude towards the quality of care services. These findings are in line with the findings of studies made by Amaghionyeodiwe[23] and Amery et al.[24] in Nigeria and Iran, respectively. However, Amery et al. reported that the main

factor behind preferring private hospitals over public ones was the quality of care,[24] while Amaghionyeodiwe noted physical distance and financial issues as the most significant factors.[23]

We also found that parents were not actively involved in the process of treatment and care delivery to their hospitalized children so that they were even almost unfamiliar with the concept and the nature of participation in the treatment of one's own child. They simply defined participation as constant companionship with their hospitalized children and thus, had no significant role in selecting their physicians and deciding on treatment options. One of the major factors behind such poor participation was their lack of knowledge about cancer and its treatments. Almost all the participating parents tended to attend their children's bedside in order to make sure of the quality of care services and believed that such constant attendance had positive effects on themselves and their children. However, Ames et al.[25] and Lam et al.[26] equated participation with lengthy stay in hospital and active involvement in care delivery to children.

Another finding of the study was the role of accommodations in alleviating sufferings. Most of hospitalized children's parents stay in hospitals with their children for long periods of time. Therefore, hospitals are expected to provide them with adequate accommodations during their hospital stay. Creating a favorable environment prevents hospitalized children's parents from experiencing added suffering other than the suffering related to their children's illnesses. Previous studies also showed that environment could affect individuals' behavior. For instance, a favorable environment can help them manage their stress.[27] Besides, findings of the present study revealed the significant roles of play and entertainment in boosting sick children's morale and rendering hospital environment tolerable for them. Bolton and Bass also referred to play therapy as a means for enhancing children's ability to cope with hospital environment and conditions.[28]

The findings also indicated that the parents had limited knowledge about their children's illnesses and received little, if any, educations from healthcare providers. Kirou-Mauro et al. also noted that the major challenge of cancer patients' family members was lack of knowledge about cancer.[29] Children with specific diseases such as cancer are very vulnerable and thus, minor care-related errors may result in serious problems for them. Consequently, as children's chief caregivers, parents need to have and receive detailed information about how to look after them. Other studies have also highlighted the importance of patient and family education and reported that it can positively affect families' ability to evaluate and manage cancer-related pain.[30,31]

Another finding of the current study was related to the effect of other parents' presence. Factors such as healthcare providers' heavy workload and their inattention to families' problems and needs as well as poor relationships between them and parents had prevented the participants from considering healthcare providers as a good source of peace and serenity. However, given to their shared experiences, parents had much stronger relationships with each other. Trimm and Sanford also found that parents who had similar conditions usually supported each other and positively affected each other's morale.[13]

We also found that most of the participants were profoundly shocked by cancer-induced great psychological stress and pressures. In agreement with this finding, Wu et al. reported that the diagnosis of cancer produced many negative effects on children and parents' physical and psychological health.[32] The study participants' major strategy for achieving serenity and alleviating psychological

pressures induced by their children's illnesses was to establish strong relationship with God. Spiritual interventions have been reported by previous studies as effective coping mechanisms for alleviating psychological distress, reducing feelings of anger, guilt, and despair, enhancing inner peace, and boosting hope among the parents of children with cancer.[33,34]

Another finding of the study was indetermination-induced suffering. The main reason behind the participants' indetermination was their lack of knowledge about their children's health status and the prognosis of their illnesses. Naifeh Khoury et al. also reported that Lebanese parents suffered from indetermination and fear over future.[12] Parents of hospitalized children have the absolute right to receive educations about their children's problems. Nonetheless, healthcare providers in the study setting refrained from providing such educations due to uncertainties over the diagnosis of children's problems or in order to avoid adding to parents' stress. Oskouiee and Gavgavni stated that providing information to patients improved the quality of patient care, accelerated recovery, reduced medical errors, prevented rehospitalization, and enhanced patient satisfaction.[35] Wills also found that information provision by physicians calmed anxious and agitated parents.[36]

The other study finding was lump in throat. The unfavorable atmosphere of hospital settings and the critical conditions of their children had brought the participants with awful feelings of fear and anxiety. Lack of psychological support for these parents results in different concerns for them, increases their stress, and reduces their ability to care for their children. Consequently, all the participants noted that they needed a source of adequate support. However, healthcare providers' poor relationships with them had prevented them from receiving support from physicians and nurses. According to Jadidi et al., effective human interactions between parents and healthcare providers help fulfill parents' emotional and psychological needs and indirectly affect the flow of treatments.[20]

Conclusion

The risks and complications of cancer cause many frustrations and psychological stresses for the parents of children with cancer. Parents should manage these pressures in order to care for their child. The findings of this study revealed that the parents of children with cancer had negative experiences of their children's hospitalization such as healthcare providers' inattention to them and their needs. Besides, they suffer a lack of support, particularly during the early phases of their children's illnesses. It is recommended that these parents become more actively involved in the process of clinical care delivery in order to play a more significant role in their children's recovery from cancer. Moreover, effective systems need to be developed to emotionally and psychologically support these parents.

Conflict of Interests

Authors have no conflict of interests.

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